

Flip my two-headed coin

by ROBERT DE ANDREIS

I'm at that curious place in my illness where I don't care whether I live or die, and I say that with a smile on my gaunt face. The chemotherapy is killing me faster than the pulmonary KS and my good days are dull days; dreary, irritating and surrounded by people I hardly know.

Can you imagine spending the last, most intimate moments of your life with trained strangers? Lately, I've been seeing my brother, David, who has taken it upon himself to spend one night a week over here. I'm also seeing my folks for a rare lunch visit tomorrow; I'm too tired to be mad at anyone any more. But besides that, there aren't any familiar faces left, just extra-helpful people wanting to know, a hundred times a day, if there's anything I need. So concerned, so helpful, so annoying.

I'm so vulnerable to infection right now that I can't even hug any more and need to say inside my apartment most of the time for protection against infection. There are body aches, weariness, fatigue, peripheral blindness in one eye, stomach problems and the constantly diminished capacity of my lungs and the constant coughing, to the point where I now have an oxygen tank in my living room. Nothing messes up the overall design scheme of a room more than the intrusion of unsightly hospital equipment. I asked the delivery man, "Doesn't this tank come in some kind of faux finish?"

Unless I take Ativan and a few hits of morphine, I can't sleep through the coughing. Even though I wake up sedated, I can't eat in the evening unless I've had Marinol, which leaves me with a great appetite, but at the price of being heavily stoned. Things are changing monthly, weekly, day by day. All these symptoms are manageable. I've certainly had it worse, but questions remain. How much more will I have to take and how bad will things get before they become unbearable?

I've grown weary of responding to nervous chitchat. I'm sick of reading

off the latest volunteer bulletin on my plummeting health. I hardly know the volunteers who help me. It's an alienating feeling sharing such private moments with strangers. These two years of full-blown AIDS have been the loneliest days of my life.

No, this has not been a time of love enveloping me in increasing amounts as the disease progressed. It's been a time when those closest to me have retreated to their caves, bracing for their anticipated grief, but causing more grief to me in the process. Why this cruel, irritating grain of sand, God? Certainly our dear *Sentinel* readers would have been just as easily fooled with faux pearls!

Yes, I have faith: I believe in stuff, I've taught religion in schools, I've had intense, mystical experiences. I will always have faith! It just doesn't stop the pain as effectively as morphine.

I really don't care if I live or die at this point. I've never been so ambivalent about something so important in all my life: You could flip a coin and it wouldn't matter much. I'm barely scared. I dealt with my big fears around death last year; in fact, I wrote several articles about it. I'm not senti-

mental about anything either — eventually we must say goodbye and never look back. Sure, it would be such a gift from the universe if I was allowed a full extra year of incessant coughing, pathetic weight loss, diminished vision and chronic fatigue, but if it doesn't happen, I'm sure I'll get over it.

How much longer can I write? Mostly, this column continues to be WORK. Why do some of us keep working until the end? There is no doubt in my mind that working so far into my illness keeps pushing back the expiration date. You need something to keep you going. I was so weak last week before my blood transfusion, I couldn't crank out a decent column — the flesh was all crapped out. Spend a day in my body and you'll know what I mean.

Illness alienates us from much of what we once loved, but this solitude creates a certain kind of strength. Only in stillness, when the noise of our heads and the prattling of those around us has subsided, can we hear ourselves think again. As a sick person, honor your unique position to uncover truth more readily, but don't expect to make friends and do expect to lose a few. Being terminally ill can be liberating, once you stop caring what other people think. In that climate, you can start a whole new life for yourself, creative or otherwise, AFTER an AIDS diagnosis. So never give up on yourself, because sometimes the best is yet to be.



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